

## DESCRIPTIVE STUDY ON FAMILY BURDEN AMONG CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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### **ABSTRACT**

*A descriptive study was carried out to elicit the family burden among caregivers on caring the Autism spectrum disorder(ASD) children. A total of 30 subjects participated in this study. Both genders were included to evaluate the caregiver burden through burden interview and univocal variables were collected from participants. Descriptive and inferential statistical analysis was used. The results showed that 56.7% of caregivers had a family burden. The study concluded that caring for children with ASD quite challenging for the caregivers like other disorders.*

**KEYWORDS:** Family Burden, Caregivers, Autism Spectrum Disorder

### **INTRODUCTION**

Autism has often described as an emotional roller coaster ride that commences prior to diagnosis and continues throughout life. Blessedness and sorrows are magnified during caring for a person with ASD; the impact of autism in the family is quite profound. It is a great burden on society. According to Elsabbagh et al (2012), in Asia prevalence was 13.9 per 10000 population<sup>1</sup>, prevalence estimates of ASD have shown a steady increase over the past 50 years. The first epidemiological survey conducted in the UK estimated a prevalence of 4.1/10,000 for classical Autism. Since then an increase in the prevalence of ASD is observed <sup>2</sup>. In 2012 the global mean prevalence of ASD was estimated to be 61.9/10,000 <sup>1,3</sup>. Family life is significantly altered, as every moment seems to revolve around the care of an autistic family member. Social reactions to the individual with ASD has a deep impact on the stress level of caregivers<sup>4</sup>. Often the entire family is shunned because of the caregivers may experience a wide variety of emotions every day. They may struggle to sleep, relax, rest as their mind is constantly on the child, this may have an effect on relationships.

The parents are usually really tired and depressed, showing their reactions among family and even in professional life.<sup>5</sup> They have to spend a lot of time with the child; so, they have less social contacts with the family members, relatives, and community. On occasion, the family is the victim of physical aggression of the children. Many of performance and behavior problems of children with ASD are preserved even with receiving proper health services.<sup>6</sup> Moreover, community understanding from the behavioral characteristics of children with ASD is limited or they do not understand it.<sup>7</sup>

Researchers reported that the development impairment, presented by children with autism spectrum disorders, may have several implications for the family dynamics<sup>8-11</sup>, from the physical and mental burden arising from daily life assignments<sup>12</sup>, high levels of stress and low levels of quality of life for the family members<sup>13</sup>. ASD is childhood

developmental disorders which can cause intense stress on caregivers, especially mothers, who may present as one of its consequences, the development of maternal depression, which can negatively affect both, the mother and the child. Hence investigator intended to assesses the family burden of caregivers of autistic children.

## OBJECTIVES

- To assess the level of family burden among the caregivers of the autistic children.
- To associate the family burden with the selected univocal variables (age, sex, Occupation, education, an income of the Family, relationship with autistic children, etc..)

## METHODOLOGY

Descriptive design based on the quantitative approach was adopted

- Study setting: This study was conducted in selected rehabilitation center in Trichy.
- Study Population: caregivers of ASD
- Sample size: 30 caregivers of ASD of the selected rehabilitation center
- Sampling technique: (N=30) samples were selected through purposive sampling technique.

## SCREENING CRITERIA

### Inclusion Criteria

- Caregivers who stay with the children and gave minimum one year of care to the child.
- Caregivers both male and female, who are 18 years and more.
- Mentally sound and willing to participate
- The Child should be diagnosed with autism spectrum disorder, according to specific criteria, those children caregivers only included.

### Exclusion Criteria

- Caregivers who are known the history of any psychiatric illness.
- Caregivers who do not know English or Tamil.

### Description of the Research Tool

Part I- The univocal variables of the caregivers of autistic children.

Part II –for assessment of burden family caregivers was done through the modified Brazilian scale Burden interview. This includes 22 questions that cover the area of health, social and individual life, emotional stability and interpersonal relationship. The response was scored scale ranging from 0-4. The total score was 88, <21 no burden, 21-40 = mild burden, 41- 60 = moderate burden and 61 and above = severe burden.

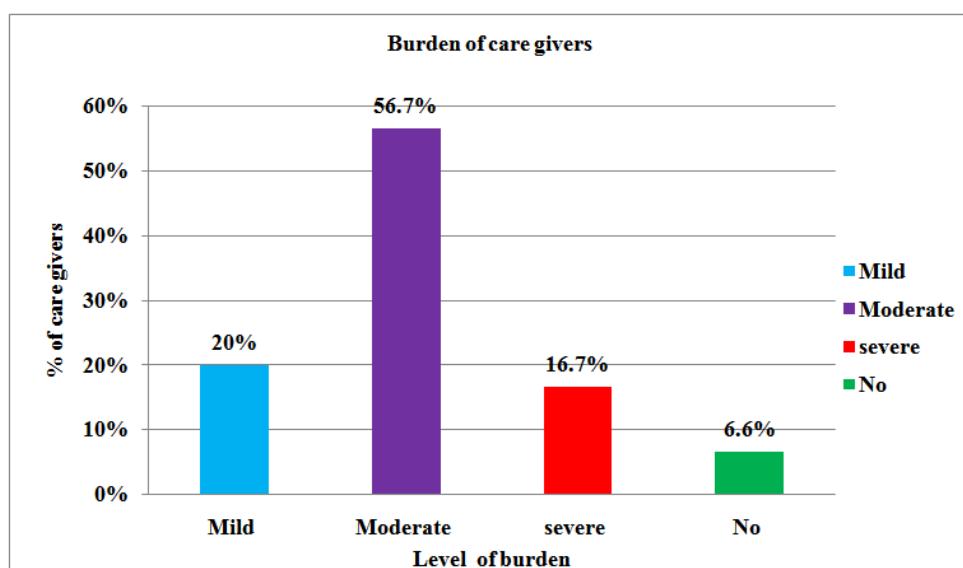
## Ethical Consideration

Ethical clearance was obtained from institution ethical committee. Formal permission was obtained from the concerned higher authority of selected rehabilitation center. Informed consent was obtained from the study participants; they were assured of the confidentiality of collected data.

## DATA COLLECTION PROCEDURE

## RESULTS AND DISCUSSIONS

Regarding the participants, it was observed that most (84%) of caregivers were females who care the children and 82% were mothers. 81% of the mothers were not working. Maybe they found difficulty in pursuing the job, it may be due to more time demanded by the child. With regard to the gender of the children, mostly (85%) of them were males. Most of the (68%) children were belonging to middle-class family and between the age of 3-5 years.



**Figure 1**

Figure 1 shows that the family burden of caregivers of Autism spectrum disorder children. 6.6% (5) of caregivers had no burden, 16.7% (5) of the caregivers had a severe burden, especially in aspects of economic burdens. 56.7% (17) had a moderate level of burden. Only 20% (6) of them had a mild burden in caring for the children. The present study result is supported by a study conducted by Andrea et al in 2015, which showed that the majority of caregivers had a moderate level of burden<sup>14</sup>.

With regard to the association between univocal variables with the level of burden among caregivers of ASD showed that age, sex, and marital status were significantly associated at  $p < 0.05$  level.

## CONCLUSIONS

Caregivers of ASD experienced burden in the financial domain and the physical domain, it was based on the severity of the condition of childhood. If they have good family support and adopt a good coping strategy they could able to care the child better and it is recommended counseling and stress management can be given for the caregivers to manage the burden.

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